

Services to Promote and Maintain the Resilience of Families with a Person with Disability

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Abstract

Background

Like any other person, a person with disability affects and is affected by their family. Thus, the whole family, together with the person with disability, experiences the systemic, social and personal effects of the disability. The family's ability to cope with these effects depends on "family resilience" - the family's ability to withstand life's challenges.

JDC Israel Unlimited, the Disabilities Administration at the Ministry of Welfare and Social Affairs (hereafter, Ministry of Welfare), the Mental Health Department at the Ministry of Health, and the Division of Special Education at the Ministry of Education initiated a joint process to strengthen the resilience of families with a person with disability. As part of this process, JDC Israel Unlimited commissioned the Myers-JDC-Brookdale Institute to conduct a study on services that promote and maintain family resilience among Israeli families with a person with disability.

Objectives

1. Review available services to promote and maintain the resilience of families with a person with disability, including:
 - a. Services for families with children, adolescents, young adults or adults with disabilities
 - b. Services provided by the government (mainly the Ministry of Welfare, the Ministry of Education, and the Ministry of Health) as well as NGOs
 - c. Services provided to the general population, and particularly to Arabs and Ultra-Orthodox Jews.
2. Identify aspects and services that require further development, including existing services and those that are lacking.

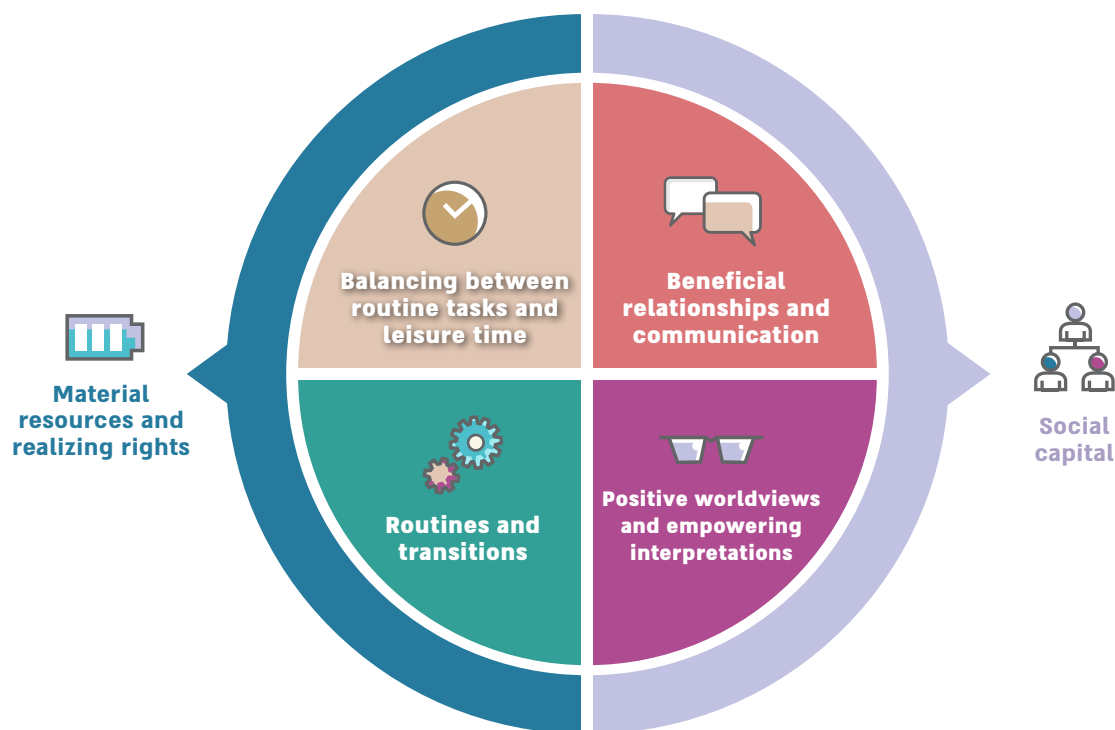
Method

1. **Consultations** with academics, professionals in the area of disabilities, government officials and social activists
2. **Review** of scientific articles and publicly available documents on the websites of ministries, municipalities, service organizations, and research institutes
3. **Thematic analysis** of 95 interviews conducted for the purpose of this study or previous studies with professionals in the area of disabilities, people with disabilities and members of their families.

The data were analyzed according to an applied model of family resilience based on a *knowledge map on family resilience* created by the JDC-Ashalim Family Area and the Ministry of Welfare's Individual and Social Services Administration and developed together with the ERI Institute.

Findings

The study's findings have contributed to the development of an **applied model of family resilience in families with a person with disability** (as shown in the figure):



Material resources and realizing rights: Family resilience includes the family's ability to optimally manage the use of its available resources and to realize its rights.

Balancing between routine tasks and leisure time: An overload of caregiving and emotional strain can disrupt the ability to dedicate regular times to leisure activities shared by the parents alone or by the entire family. In time, this is liable to erode the family's resilience.

Beneficial relationships and communication: The burden of care can make it difficult for members of the family to engage in healthy and open discourse. Support and training in positive family communication are required, especially in times of crisis and when critical decisions need to be made.

Routines and transitions: Families of people with disabilities frequently experience personal and family life transitions, sometimes even during changes in their daily routine (as in holidays or vacations) that require them to show flexibility. During transitional times, they require greater emotional and practical support.

Positive worldviews and empowering interpretations of their challenges: In order to empower the family's belief in its abilities and enable optimal collaboration and problem solving, families with a person with disability require emotional support in times of personal and family crises – from the moment a disability is first suspected, through its diagnosis, and up to the demise of the person with disability.

Social capital: Increasing the sense of social belonging and social support depends among other things on acquaintance with similar families. It is also important for forming a “disability identity” – the process of accepting the disability as a positive identity and strengthening feelings of pride, competence, and an optimistic view of the future.

The study highlighted **challenges in meeting the families' needs:** There is a critical shortage of services and interventions for parents with disabilities, for siblings, for grandparents, and for young family members caring for a family member with disability; the scope of services provided in transitional stages and emergency situations is smaller than required; and there are differences in the definitions used and the services provided by the various service providers and municipalities, particularly in Israel's socio-geographic periphery.

Recommendations

Based on our findings, action-oriented recommendations were developed in the following areas:

- Identification of family members of people with disabilities and acknowledgment of their roles
- Facilitation of access to information and coordination of care
- Removal of barriers to the use of services and reduction of gaps in service provision
- Development and improvement of services in the areas of leisure and individual well-being, as well as in providing practical and emotional support and training
- Development of a disability identity when providing family services.